

national transition support team

working together to improve transition
for disabled young people

What is Advocacy?

Based on the work of The Children's Society and Speaking Up

Introduction

This leaflet explains what advocacy is, how the role of advocates is different from other kinds of support and how advocacy can be used to support disabled young people in transition to adulthood.

Individual Advocacy

Individual Advocacy is supporting a young person to speak up for him or herself and get their views across to others. It can also mean an advocate representing the views, wishes and needs of a young person to decision makers.

*"Advocacy is about speaking up for children and young people. Advocacy is about empowering children and young people to make sure that their rights are respected and their views and wishes are heard at all times. Advocacy is about representing the views, wishes and needs of children and young people to decision-makers, and helping them to navigate the system."*¹

National Standards for the Provision of Children's Advocacy Services

Why is Individual Advocacy important at transition?

Transition is a time of change, when decisions must be made and when good communication and coordination between the young person, their family (if they have one) and service providers is vital if the young person is to maintain choice and control. Advocacy may be needed at transition for the following reasons:

- to promote better involvement of young disabled people in decision making at transition

- to ensure that young people's views are heard separately from that of their family, while maintaining family involvement
- to support young disabled people at transition who are looked after or live 'out of area'
- to promote and support emotional well-being at transition, particularly for young disabled people with mental health support needs.

What is the role of Individual Advocates during transition?

To secure rights: Advocates make sure young people know their rights and have their rights upheld. Advocates help young people understand and navigate the transition process

To make sure young people can make informed choices: Advocates make sure young people have information and advice so that they can make informed choices about their future

To empower young people: Advocates seek to ensure young people have greater control over their lives. If young people are able to speak up for themselves advocates will support them to do so. Where necessary advocates represent the views, wishes and needs of young people to decision makers.

To help sort out problems: Advocates support young people to resolve concerns or issues they may have with the people involved in their life and where necessary help them make a complaint if they are not happy about something.

To be there solely for the young person: Advocates are independent but not impartial. They are there to act exclusively on the young person's behalf. They have no other conflicting interests or pressures.

How do Individual Advocates work with disabled young people?

Advocates need the appropriate skills and knowledge to understand and communicate with each young person. They often spend extra time with the young person to get to know them and the way they communicate. This might include using sign language, visual images, observation, communication aids and equipment. Advocates working with disabled young people have to be creative and imaginative in helping the young person get their views across in whatever way is best for them. If a young person is unable to instruct their advocate about their wishes and feelings advocates can follow a non-instructed approach to advocacy. This involves observation, questioning and information gathering and representing the rights of the young person.

What difference does individual advocacy make to the lives of disabled young people at transition?

A study published by the Office for Disability Issues² found that advocacy input at transition may lead to benefits in terms of:

- increased involvement and better quality involvement of young disabled people in transition planning
- a positive impact on the behaviour and knowledge of professionals regarding disability and disabled people
- advocating for more and better quality opportunities at transition.

In relation to outcomes for disabled young people the study found that advocacy input may lead to benefits in terms of:

- personal development such as increased confidence and self esteem
- raised expectations about what is possible
- a more positive self identity as a disabled person.

Individual Advocacy in practice

Jasmine's Story

Jasmine is 15 and has been in care since she was very small. She has moved placements several times as staff have struggled to cope with her physical care needs.

In her latest placement Jasmine seemed to be increasingly in conflict with the care staff. An advocate was introduced to Jasmine and having spent some time with her away from the unit, and building up her trust the advocate discovered Jasmine was feeling really constrained by the unit's rules and routine. She felt she wasn't being encouraged to make her own decisions or make friends away from the unit. She felt the staff were being too protective of her and wouldn't let her take any risks.

Her advocate went along with Jasmine to her next review and supported her to be honest about how she was feeling. The review team arranged for the local person centred planning worker to get involved and with the support of her advocate Jasmine is now preparing for her first person centred transition meeting.

Individual Advocacy in practice

Asim's Story

Asim is 16 and attends a local special school. Plans had been made some time ago for Asim to move to a residential college but as the time was getting closer his teacher felt he was becoming more and more withdrawn – quite unlike his usual happy personality and he wasn't willing to discuss the move at all. The teacher discussed this with his parents but they didn't seem concerned. Despite encouragement from the staff Asim refused to attend his next transition planning meeting.

The school arranged for an independent advocate to meet with Asim to try and get to the bottom of his sudden change in behaviour. After a few sessions it became apparent that Asim was very unhappy about going away to college and had only gone along with the plan because he felt it was what his parents wanted. He didn't feel he had any choice. A further planning meeting was arranged and the advocate supported Asim to explain how he felt. It was a difficult and emotional meeting but everyone, including his parents agreed in the end to put the plans for the move on hold until Asim had had the chance to consider some other options.

The advocate continued her involvement for six months and supported Asim to think through for himself what he really wanted. He considered a work placement scheme, the local college and had an overnight stay at the residential college. Asim finally decided the residential college was for him and was looking forward to moving there albeit 6 months later than originally planned.

Individual Advocacy in practice

Frankie's Story

Frankie is 14 and spends long periods of time in hospital as a result of his complex health needs. Many different staff support his daily care needs. Frankie uses the Picture Exchange Communication System [PECS] when he is at home and when he is well enough to go to school.

Frankie was referred to an advocate by the SENCO at his school. The advocate soon realised that he had no pictures in his PECS file that related to the environment in hospital and as a result was struggling to communicate his preferences to the hospital staff. Once this was rectified the nursing staff were able to use the pictures to help explain to Frankie what was going to happen next in relation to his treatment. The advocate made sure Frankie had a transition review meeting even though he had not been in school for quite a while and helped Frankie prepare two important things that he wanted to say at the review using pictures and symbols.

Other forms of advocacy

Informal Advocacy

Lots of different people may advocate informally for children: friends, relatives, teachers, school nurses, social workers, foster carers, independent visitors. They may represent children's views or use advocacy skills such as negotiating or advising but they are not always independent of those making decisions, they are not always there just for the young person and they may have their own views to put across.

Natural Ally

A Natural Ally is someone chosen by the young person who already understands their means of communication and is willing to advocate for them. Training and support for the advocate are given by an organisation.

Peer Advocacy

Advocacy is provided by someone of a similar age who shares or has shared a similar experience to the young person. They work on a one to one or a group basis and are supported by an organisation. They can offer a more equal relationship and act as a role model.

Citizen Advocacy

Citizen advocates are volunteers in the local community who are supported and trained by a co-ordinator. They offer a long-term relationship to their advocacy partner.

Self Advocacy

Involves young people collectively advocating on their own behalf and supporting each other to self advocate. Self advocacy groups are usually supported by organisations such as Speaking Up and The Children's Society.

Resources

Further information about advocacy for disabled young people, including a number of tools developed to promote advocacy, is available from the following websites:

Action for Advocacy

www.actionforadvocacy.org.uk

The Children's Society

www.childrensociety.org.uk

Disability Toolkit (The Children's Society's online database of resources to support disabled children to participate)

www.disabilitytoolkit.org.uk

Speaking Up

www.speakingup.org

Triangle

www.triangle.org.uk

Voice

www.voiceyp.org

References

1. Definition taken from the National Standards for the Provision of Children's Advocacy Services, Department of Health 2002
www.dh.gov.uk/dr_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4018893.pdf
2. Townsley R, Marriott A and Ward L, 2009, 'Access to Independent Advocacy: An Evidence Review', Office for Disability Issues.
www.officefordisability.gov.uk/docs/res/iar/iar-full.pdf

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To find out more about the National Transition Support Team and the Transition Support Programme:

Information line: 020 7843 6348

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www.transitionssupportprogramme.org.uk

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